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ABSTRACT

This case study describes the 2-year process of moving a young child with severe disabilities and complex medical needs from a special school setting to a special class in a regular education setting. The child had Marshall-Smith Syndrome, characterized by respiratory, pulmonary, and skeletal abnormalities, and developmental delays due to the coexisting condition of "failure to thrive." The account reviews the initial efforts to place the child in a public school program at age 3, the literature on least restrictive environment, the boy's background, the residential facility and its educational services, and initial rejections from the public school system due to his parents' lack of local residency. The importance of whether the child was labeled severely/profoundly handicapped or trainable mentally handicapped and the effect of this labeling on his qualifying for specific educational services are discussed. The conflicting interpretations of the Illinois School Code, the influence of the Advocacy and Guardianship agency, and his eventual placement in a self-contained class for severe and profoundly handicapped students within a community elementary school are then described. Further discussion notes problems raised by the presence of a residential facility for children with severe disabilities and complex health needs in a community embracing inclusion. Appendices provide supporting letters and documents. (Contains 16 references.) (DB)

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TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

Alex in the Middle: Inclusion of a Child with Severe Disabilities and Complex Health Needs

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EC 305410

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"Stop that!!" Helen Morris* exclaims. Helen is the Qualified Mental Retardation Professional (QMRP is an Illinois designation for certified teaching personnel in a residential facility. QMRPs teach in the classroom and are also responsible for a variety of administrative duties) for the elementary aged classrooms at Sterling Special Care Center (SSCC). She has been on staff for eighteen months. Helen brings a wealth of knowledge and experience with young children with severe disabilities both within the public school system and private facilities. The adjoining classrooms are filled with posters and student-made (with teacher assistance) art on the walls. All of the children are classified as functioning within the severe to profound range of delay. A total of eight children are in this classroom. The age range is approximately four to ten years old. The children on the other side of the bathroom/changing room/storage area are slightly younger. Most of the children rest on elevated mats that line the perimeter of the classrooms. Physical activity is limited due to medical and orthopedic conditions that necessitate monitoring and strict positioning protocols such as those for seizure disorder and hip displacement.

Helen's room is dwarfed by the amount of equipment and number of staff that filter in and out. At any one time, one to two classroom assistants, one to two physical therapy personnel, and members of the nursing staff converge. Medications are administered, orthopedic regimens are implemented, and, educational instruction is provided. The room is often noisy from voices including staff, children, tape player, and television as well as medical machinery including breathing monitors, tube feedings, and humidifiers. It is not atypical to find the children being assisted to explore tactile objects,

* Pseudonyms are used throughout to assure confidentiality and anonymity.

activate a tape recorder or other specialized device, or participate in self-care routines (i.e. hairbrushing, lotion application, etc.). All of these activities are written in the form of instructional programs; a behaviorally oriented method requiring specification of learning objectives, reinforcement schedules, and level of assistance.

Helen is directing her comments to Alex, a cherubic looking four year old who has once again been discovered in the middle of something that he should not be doing. He has entangled himself in the tubing of another child's humidifier (a long piece of tubing that is connected to a tracheostomy). Tracy shows little response to Alex's vigorous pulling but the tube's attachment to the rest of her machinery appears tenuous. Alex turns toward Helen and gives her an ear to ear smile, the type that makes it difficult to remain angry. Yet, Helen, by this point irritated by his antics, repeats her earlier entreaty. Alex continues to tug on the tubing and grin. As Helen approaches, he moves along the floor using his bottom for propulsion. Alex strikes an angelic pose and begins to play with a book that he finds on the floor next to him.

Until approximately a year ago, Alex spent most of his time in a donut shaped mat such that he was able to move around but the elevated sides deterred him from climbing out. It was set up for a child who tired easily but was both aware of and interactive with his environment. As his health improved, greater demands were placed on him. He spent longer periods of time sitting in a specially designed chair with a lap tray so that he could participate in instructional tasks such as turning pages in books, removing and replacing objects from containers, and imitating simple signs. He also became more social and responsive to adults. He appeared to view his classmates as little more than obstacles in his path or interesting things to explore, especially their medical equipment.

Background

Setting the Stage

In March of 1996, I was supervising a student teacher in Helen's classroom. She was an undergraduate studying in the area of moderate and severe disabilities at a large midwestern university. One of her assignments was to write up a plan in order to provide solutions for a Classroom Programming Problem.[1] She approached me with the following problem: improving Alex's social skills. The majority of his interactions were directed toward adults. He took little notice of his peers except to play with their machinery and/or to take their toys. Christine told me that Helen had been telling her about the need for him to interact more with peers. In addition, staff members did not encourage him to initiate or maintain more age-appropriate reciprocal exchanges. They reinforced his overtures but at a level not appropriate to his functioning as well as not appropriate in other potential settings. For example, Alex often initiated interactions by tugging on clothing or pulling hair.

In a setting such as Sterling most exchanges are between staff members and limited to observing children's responses to activities, such as music or other types of sensory stimulation, or to administer procedures, such as medication or tube feeding. I have seen the similar things in a skilled nursing facility setting in New York City. The children did not notice one another unless adults intervened and/or encouraged play through sharing of materials and the like. In addition, many of the children at both Sterling and a similar facility in New York City were functioning with cognitive and

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[1] Renzaglia, A., Chadsey-Rusch, J., Halle, J., & Lee, S. (1995-1996). p. 74 Undergraduate Practicum Handbook for the Moderate and Severe Disabilities Personnel Preparation Program.

motor delays that inhibited interactions with objects or people in their environments such as sensory deficits and limited voluntary movements.

Alex, on the other hand, was able to scoot around the classroom, handle objects, and vocalize throaty sounds through his tracheostomy. He was extremely responsive to adult stimulation of any type. The adults in his classroom along with others in the facility (i.e. nursing staff) were his only social contacts. Helen and Christine's request made me wonder. How would this be encouraged in such a setting and why?? Then, I remembered a conversation with Helen Morris. She approached me about helping her find a way to secure a placement for Alex in the public school system in town. Being new to the area, I politely declined but said I would assist if I could. The Classroom Programming Problem was aimed at improving his social skills as a way to prepare him for an eventual placement in a classroom outside of SSCC. Little did I know that the process, a culmination of two years effort, was close to fruition.

I encouraged Christine to read literature about strategies to facilitate peer to peer interaction and to think about possibilities for their implementation in Alex's classroom. We discovered that the first area to target was staff's interactions with Alex. As Christine noted, the adults tended to treat him as a younger child and thus limit his opportunities for social interaction and development. My observations concurred, "socially he is focused on adults. Peers are more delayed and it is difficult to set up situations [to encourage interaction]. 'Babied' by staff then told to act like a big boy. He does some initiating but sometimes withdraws from tasks or demands from adults."[2]

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[2] Supervision notebook entry, April, 1996, author.

As part of her assignment, Christine developed several solutions and prioritized them for classroom use. Among them were the following recommendations: (a) staff would selectively reinforce age-appropriate social behaviors, (b) environmental arrangement strategies would be implemented such as use of preferred toys to encourage reciprocal interactions and use of signs, and (c) generalization of the above strategies in a more inclusive setting.[3] All of these strategies are recognized in the literature as facilitating the acquisition and use of age-appropriate social skills. The last one is particularly salient in that it acknowledges the need for opportunities to practice these skills in a setting unlike SSCC. For a child with severe disabilities, learning for generalization requires occasions to utilize skills in different contexts with different individuals including teachers, peers, and other staff.

Helen also wanted Alex to have more exposure to typically developing peers. She felt the same way as Christine about staff "babying" Alex and the need for him to improve his skills in ways that Sterling could not provide due to the population served there. Helen continued, "Alex was really not appropriate for this setting and that he needed to get out and get into regular public school. . . right now his main pleasure is manipulating adults and he's had five years to do that. . .could probably be a little more age-appropriate [if he was attending school outside of SSCC] than he is right at this point."[4] As I continued to probe deeper into Helen's viewpoint, it appeared evident that she embraced both the theory and practice of inclusion as well as placement in the least restrictive environment (LRE).

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[3] Classroom Programming Problem Assignment, April 15, 1996, student file.
[4] Interview with author, October 16. 1996.

What the Experts Say

In the past decade, a movement has emerged that advocates for the inclusion of children with severe disabilities in their neighborhood schools. (cf. Brown et al., 1989). Proponents stress the positive outcomes associated with the receipt of services in a setting as close to that of typically developing peers, particularly in the area of social development (cf. Brown et al., 1989; Ferguson, 1995; Hunt, Farron-Davis, Beckstead, Curtis, & Goetz, 1994; Karagiannis, Stainback & Stainback, 1996). For children with special health care needs in addition to severe levels of delay, inclusion can raise problematic issues (York & Tundidor, 1995). The authors found that educators often questioned the appropriateness of regular education placement due to complex medical needs, behavioral characteristics of the child, and the lack of full-time nursing assistance. Several authors have come out against the push toward inclusive environments for all students (cf. Fuchs & Fuchs, 1994; Jenkins, Pious, & Jewell, 1990). The main point rests on the need for "creative thinking" on the part of the individuals involved in inclusion efforts in order to make sure that the placement is able to meet the needs of the student and not the reverse (Villa et al., 1995). This thinking often takes time to develop (Janney, Snell, Beers, & Raynes, 1995).

The concept of LRE has been defined as "the legal principle that students with disabilities are to be educated as close as possible to the general education environment. . .The law requires that each student be educated in the environment that is the least restrictive for that student. . ." (Osborne & Dimattia, 1994, p. 6-7). This has also come to mean that children are to be served in settings that are responsive to their needs as well as similar to those received by their non-disabled peers. LRE is viewed as a theoretical

framework with inclusion in regular education settings as a possible outcome. The two are intertwined and must be understood in terms of the sometimes uneasy balance that is necessary for the former to be understood for the implementation of the latter to succeed. Researchers and practitioners in the field of early childhood special education caution about the difficulties in achieving inclusive placements without support from all individuals involved (Bricker, 1995; Peck, 1995; Strain, 1990).

The Main Player

This case study was undertaken to combine the preceding aspects related to the theory of least restrictive environment and the practices pertaining to the applicability of inclusive services for a child with severe disabilities and complex medical needs.

Medical and Social Information

Alex was born with a rare syndrome which affects his pulmonary and respiratory systems as well as necessitates gastrostomy feedings due to the coexisting condition of failure to thrive. He requires around the clock monitoring due to his medical needs. In addition, children with Marshall-Smith syndrome, so named for two of the physicians who involved in the syndrome's initial description (Marshall, Graham, Scott, & Smith, 1971), display a pattern of identifiable features. Accelerated skeletal bone growth is manifested in long fingers, large head circumference, and other types of skull malformations. Dysmorphic features (low nasal bridge, low-set ears, and prominent eyes) are additional characteristics. Finally, the life expectancy for children with this syndrome has typically been only one to two years (Johnson, Carey, Glassy, Paglieroni, & Lipson, 1983; Visveshwara, Rudolph, & Dragutsky, 1974).

Alex was placed at SSCC when he was eight months of age. His parents were no longer able to care for his complex medical needs. Over two years ago, efforts were initiated in an attempt to change his educational placement to a less restrictive setting. Up until that time he had been sickly and prone to long periods of hospitalization for pneumonia and related illnesses. His skills were also severely limited in all developmental areas. During the second half of the 1995-96 school year, his health began to stabilize. He became increasingly aware of and interactive with his environment. On evaluations, Alex was found to be performing at higher levels than most of the other residents at the facility. Alex was progressing, slowly but progressing. Each improvement took time and many opportunities for skill acquisition. New strategies were used to encourage his learning. The most striking change was in his communicative abilities. For the first time Alex was initiating interactions and expressing preferences by gesture (beginnings of sign language for words such as "play" and "more"), physical means (i.e. grabbing at clothing), and increased vocalizations through his tracheostomy.

In relation to other SSCC residents, Alex is higher functioning in terms of his cognitive, language, and motor abilities. Over one hundred children and adults from all areas of Illinois live in this specialized medical setting. Nursing staff provide twenty-four hour care. Therapy is furnished through on site personnel and consultants. Each resident follows plans prescribed by the health professionals involved in his or her care. Compliance with positioning, feeding, and other regimens are mandatory and take up a majority of the residents' waking hours. For example, most residents follow a two hour up, two hour down schedule to reduce the amount of time spent positioned in their wheelchairs and other adaptive seating systems. Positioning is adjusted every two hours

to prevent bone and muscle atrophy as well as increase participation in planned activities during school and recreation sessions.

The Facility and Educational Services

SSCC is located in a college town comprised of two neighboring areas (Nelson and Anadale). In this community, children with disabilities receive most educational and support services (i.e. physical therapy, speech therapy) in inclusive classrooms. At SSCC, children attend the in-center school which offers full-day sessions within the building. A few students go to schools in the community based on recommendations from SSCC staff and evidence of stable health status. Outside school is also based on space availability and an agreement between the neighboring areas as far as services for particular populations of children with disabilities.

When a resident is determined to be medically stable, a recommendation is made by the team at SSCC (including nursing staff, QMRPs, and therapists), parent(s) if involved in their child's care, and consultants such as psychologists, to attend outside school (outside of the in-center program at Sterling). A formal referral called a request to enroll is made to the school district. Although SSCC is located within Nelson's borders, most residents deemed eligible attend public school classes in Anadale. As explained by administrators in both districts, Nelson primarily accepts children with sensory impairments (i.e. hard of hearing) while Anadale serves children with multiple disabilities. For the latter group, placements are typically in self-contained classrooms within a community public school.

SSCC has a history of successful community educational placements for its residents. Presently, coordination between SSCC and the receiving school and classroom

teacher(s) is facilitated by Dan Johnson, the QMRP responsible for all residents served in outside placements. Dan has been on staff at SSCC for four years. In that time, he has overseen many successful referrals. Prior to 1994, the process was decentralized. The QMRP accountable for each particular child coordinated the referral process and communication with the corresponding receiving school and classroom. This often created fragmented communication and difficulties in coordination. The centralized structure has made the process easier for all involved.

Getting Started

During the Fall of 1994, a request to enroll was made for Alex. This was initiated for several reasons. Alex had reached three years of age, signifying his eligibility for receiving preschool special education services in a public school setting. Second, his health had stabilized to the point that attending school outside of SSCC was a viable option. Third, several members of his treatment team had recommended such a placement, notably Helen Morris and the speech and language consultants who had been working with Alex since he was first admitted to SSCC.

The referral was sent to the Nelson public school system after Dan Johnson spoke with Hope Duncan, social worker for twenty years for the severe and profound handicapped (SPH) program in the Anadale public schools. Hope advised Dan to contact Nelson schools due to Alex's status as a trainable mentally handicapped (TMH) child thus fitting the criteria for Nelson's preschool program. Nelson does not have a program for severely and profoundly handicapped (SPH) preschoolers. Most SSCC residents fit into the latter category. Preschool-aged children in the district attend one of two programs

geared to meeting the needs of youngsters with mild disabilities or delays (i.e. delays in speech or language development).

The Refusals

In a letter dated September 20, 1994, Jan Marx, Director of Special Education for Unit School District No. 4 in Nelson, stated that Alex was not eligible for placement for the following reasons,

> the first is that the additional supports and aides required to serve this student is beyond our current resources as we are at capacity serving our own students. The second reason is that we are very committed to serving students in their home schools [referring to schools in the county where the child and/or his family resides] and accepting tuition students creates an unequal proportion of students with severe disabilities in these school. (Appendix A)

The preschool program in Anadale accepts a wider range of children and disability levels than Nelson but with priority given almost exclusively to residents in the district. A formal letter was sent to the Anadale preschool seeking a placement for Alex. Barbara Caldwell, Assistant Director of Special Education for Anadale School District 116, sent the following reply on February 8, 1995. She writes,

> After having looked at the psychological report, it appears that Alex would be eligible for services in the Anadale SPH program. However, at the present time, we have no slots available for out of district students in our preschool SPH program at Washington School. We may have a slot for Alex in the 95-96 school year, so feel free to contact us next fall to inquire about this possibility. (Appendix B)

Hope Duncan advised Dan to continue to advocate for Alex's placement regardless of the refusals from both Nelson and Anadale. Dan comments, "in the past, with Anadale, there was never a problem with our residents because they had space available. But with Alex there was no space available and that's where it turned into it's Nelson's responsibility, not Anadale and that's where the problems began. . . . Fairly easy process until the space

issue came up."[5] During this time, Hope Duncan also sent a letter to Brenda Sinclair, Director of Special Education for Anadale requesting a clarification of Nelson and Anadale school district procedures and practices for students residing at Sterling who are referred to public school.

Special Circumstances Explained

The admission of a child from a school district outside of Nelson County raises several issues. Alex's family resides in a nearby county, qualifying him for educational services through his home district. Tuition fees can be paid by the child's home district to Nelson County once a decision is reached to allocate the funds. Then, it is up to the Nelson County school district to accept the child for services. Priority is given to children living within the county although a special stipulation is made for children with physical disabilities residing outside of the county whose schools are not wheelchair accessible. These children are accepted on an as needed basis.

Another special circumstance is accepting children from Sterling into Unit School District No. 4 when they are under the supervision of the Department of Child and Family Services (DCFS). As explained by Jan Marx[6] , once parental rights are terminated (due to neglect, abuse, foster care or adoption), the children are automatically eligible for services in Nelson. Alex's parents' participation in his care was actually limiting his placement options. Hope Duncan articulated the phenomenon in this way,

> The point I kept making is inclusion is supposed to be providing opportunities for people and we by being more inclusive are closing this child out and that this child has no choice of where else to live. His parents would be taking him to his local district if that choice existed. That choice doesn't exist. DCFS taken on space available basis unless child is from Nelson or Anadale. Basically, the message we are providing to these parents is if you give your child up and place them with DCFS there would be no question. That is a fact. If DCFS had his custody it would be a non-issue. Either Nelson or Anadale, one

[5] Interview with author, October 24, 1996.
[6] Interview with author November 15, 1996.

of these districts would have to agree to take him provided he is medically eligible to attend school. That is one of the reasons I kept pursing this. It isn't really just an Alex issue, it is a far-reaching issue. These kinds of kids are everywhere and are being punished because there's not living arrangements for them in their home community, their home school district where their parents or guardian live is who is responsible.[7]

Hope's comments illustrate the irony inherent in the need for specialized care outside of the home coupled with limited options for educational services in the Nelson-Anadale community. Helen Morris explained the situation in this way, "If the parents would give up the rights to the kid and give them to DCFS then they'd [Nelson County] have to cover him . . .most parents don't want to give up the custody of their kids, their rights to their kids."[8]

Neighboring counties deal with this matter in other ways. Children living in a residential setting in the Springfield area, for instance, are able to attend the local schools with little discussion of district priorities and overrepresentation of students with severe disabilities. There is another instance of a SSCC resident attending his county school by way of an aide who drives him forty-five miles each way daily as well as assists him in an inclusive kindergarten classroom.

As Alex became increasingly medically stable and continued to outlive his life expectancy, the staff at Sterling wanted him to participate in activities outside of the facility. Helen Morris was the one who initially approached Alex's parents with the idea of placement in a community public school.. His parents were in agreement for a more inclusive educational setting. Yet, it appears that their involvement actually hindered the progress of Alex's placement outside of SSCC. What type of message is this sending to

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[7] Interview with author, October 17, 1996.
[8] Interview with author October 16, 1996.

parents? Nelson County will accept a child without argument if he or she is under the protection of DCFS but questions placement for a child who has parental backing and financial support from their home county. Nelson's priorities appear not to be either "family-friendly" or "child-focused"[9]

The child is caught in the middle of this predicament until the adults (Nelson County school district administrators, home county school district administrators, child's parents, and SSCC personnel) are able to reach consensus. A major component of Public Law 99-457, which mandated educational and related services for children with disabilities or at-risk for delays under the age of five, was to serve children in least restrictive environments such as community day care and public school settings. Parents were encouraged to increase their participation in all facets of the educational process (including assessment, placement, and evaluation) and to be viewed as part of the educational team instead of as passive recipients of services. In Alex's case, this involvement proved to be a disadvantage.

Getting Started Part Two

The staff at SSCC pushed on. On December 27, 1994, a letter was sent to Alex's home district from SSCC advising the Director of Special Education of the possibility of outside placement. The refusal from Unit School District No. 4 in Nelson is mentioned as well as the tuition issue. The letter also notes that "Alex is one of our highest functioning

[9] Denote phrases commonly used in the early childhood special education literature to illustrate best practices concerning interactions between school personnel and parents in order to achieve optimal child and family outcomes.

residents and personnel at SSCC feel that public school placement would be beneficial for him."*

An Alternative

Plains School in Anadale is offered for consideration as an alternative public school placement to preschool programs in the district. This was the outcome of a multidisciplinary committee (MDC) meeting involving primarily SSCC personnel. The MDC meeting is held before writing a child's new educational goals and objectives or Individualized Education Plan (IEP). This meeting generates and prioritizes educational instruction and services for the following school year. Invitations had been extended to personnel from Alex's home school district as well as those from Nelson and Anadale. Hope Duncan attended along with the social worker and school psychologist from Lynchberg County. A written report was sent in place of the school psychologist from Nelson who is typically present at MDC meetings.

The change from Washington School, which serves preschoolers, to consideration of Plains School, which serves kindergarten and elementary-aged students, is an interesting one. Why change the placement option to a kindergarten in an elementary school with self-contained, rather than inclusive classrooms? As Hope Duncan explained,

> Alex is one of those children [that] because of his birth date he's not kindergarten age now [referring to time period this was occurring—he was four]. Which means in reality for him to come into our elementary building as a kindergartner he had to come the next year. He's not a kindergarten kid. He had to be waived to come into our building as an early childhood child like our old system in order to get him into school. That is eventually what happened. [10]

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* Available from author.

[10] Interview with author, October 17, 1996.

Preschool-aged children with disabilities were accepted into Anadale's early childhood program regardless of their county of residence. It was a cooperative system, not a local one. All of the SPH children reached elementary school age at around the same time and returned to schools in their home counties. From that point on, admission to the early childhood program became limited to Anadale children. It was a space issue, not a funding one. Money was available from other school districts to finance tuition but Anadale decided to restrict this service solely children in their own district.

The classroom at Plains was designated as a kindergarten but served a mixed age grouping of SPH children. When asked about this, Dan Johnson explained that calling the placement kindergarten meant "calling it whatever they needed it to" in order to secure a placement for Alex. In special education, children are placed in three year chronological age groupings. The classroom at Plains provided services for younger elementary school-aged SPH children. Alex would be the youngest child in the classroom. A waiver from the Illinois State Board of Education (ISBE) would allow Alex into the classroom although he was chronologically six years younger than one of his classmates. Consideration was not given to the regular education kindergarten as a placement option. The consensus was that Alex would not be ready for that type of environment but might progress from the self-contained classroom into a more inclusive setting at a future time.

Little Progress

During the following ten months, Nelson County public school personnel remained silent. It appeared that the administrators hoped that the issue would resolve itself without further action. Dan Johnson continued to have phone and in-person contacts with Hope Duncan. He also had informal contacts with Barbara Caldwell during

conferences for other SSCC residents attending Anadale schools as well as during visits to SSCC. He tried to contact Jan Marx by both phone and letter. "My feeling [is] that [Nelson personnel] don't return phone calls thinking maybe they'll get tired of trying to call us. There were times when months went by [between contacts]."[11]

During the same time, members of Alex's care team at SSCC were assembling reports documenting his progress and continuing to press for the need for outside placement. During the Fall of 1994 and the following winter, staff advocated for an outside educational placement for Alex. His interim IEP, completed on February 17, 1995, states that a homebound instructional program "would not meet his needs at the present time" This is in contrast to an IEP from the previous November which stated that a private day program, referring to the services offered at SSCC "meets [Alex's] needs and [his] parents are satisfied with school placement at Sterling Special Care Center at this point" It was during this approximately six month period that Alex's health significantly improved and he began to exhibit a marked increase in his skills.

Reports from direct care staff contained recommendations for Alex's placement in a less restrictive setting as well as additional opportunities to interact with peers without disabilities. For example, a consulting occupational therapist as well as a speech language clinician wrote that Alex would benefit from placement in a public school setting. In the latter, the prognosis and recommendations sections suggest educational placement in the least restrictive environment with age appropriate peers in order to facilitate Alex's communicative development. The clinician writes, "prognosis for increasing functional communication skills appears to be fair to good if Alex receives the services outlined

[11] Interview with author, October 24, 1996.

below. Without the appropriate services prognosis is significantly poorer" (Appendix C). It would appear that Alex's developmental gains hinged upon placement in a setting that afforded him opportunities for increased peer interaction as well as improved outcomes in terms of his functioning level. Oftentimes, for young children with severe disabilities, a label of decreased functioning leads to reduced expectations and limited choices in terms of educational and rehabilitative options.

The Meaning of Labels

The labels SPH and TMH are not to be cast about lightly. Both carry weight in the formulation of educational goals and services as well as considerations for future rehabilitative efforts. Residents at a facility like SSCC typically function at levels requiring total assistance for all self-care and instructional tasks. A higher functioning level, such as TMH, indicates functioning in the trainable mentally handicapped range (approximately three standard deviations below the mean IQ score of 100), and affords greater potential for learning and independence in educational instruction and/or life skills such as dressing and grooming tasks. It is interesting to note that various reports presented contradictory findings as far as Alex's overall level of functioning. This often occurs as a child ages chronologically and the delays become more evident. This can occur over years or months. In Alex's situation, the label attached to his functioning level made a difference in determining if he qualified for specific educational services. Some people favored a self-contained setting while others advocated for inclusion.

For Alex, the difference between identification as TMH and SPH was correlated with the availability of options in a less restrictive environment. If Alex tested as TMH, he had several options. Scoring in the SPH range carries with it a weaker argument for

placement in an inclusive setting. Even though the literature argues for the placement of individuals with severe disabilities into their neighborhoods (cf. Brown et al., 1989), the reality of implementation is not as rosy. Barbara Caldwell pointed out that Anadale viewed him as more capable than Nelson (the latter thought him to be too severely disabled for entry into their preschool program).[12]

Here We Go Again

Although resolution seemed only a remote possibility, SSCC personnel and Hope Duncan pushed on once again.

In a summary of Alex's likes, dislikes, strengths, and needs, specific mention is made of the need for daily access to peers without disabilities. The report, written in October of 1995, states that the interdisciplinary team (IDT--comprised of the treatment team involved in the MDC meeting and the development of the IEP) felt that Alex is very appropriate for public school and would benefit a great [deal] from an early childhood program. Representatives from Alex's home school district will be pursuing public school enrollment in Nelson.* It is interesting to note the continuing insistence on the part of SSCC staff on placing Alex in the Nelson public schools. Contact with Nelson personnel remained minimal and the outlook unchanged for a placement. In addition, space was still unavailable in Anadale. The tenacity of SSCC personnel attests to their belief that Alex deserved placement in a more inclusive environment. As Dan Johnson explained,

"first case in two years that I had experienced a refusal from anyone. Prior to that I had probably placed probably about ten students in the Anadale system pretty much

[12] Interview with author, November 14, 1996
* Available from author.

flawlessly. And this was the first case, I actually got upset when we got the first letter and then became really frustrated after that. Not meeting with anybody was very frustrating just getting very informal letters just stating no without ever seeing Alex or even, it seemed like they didn't even think about it. They just said no, we're not going to do that. Since we see Alex everyday, no one ever really gave up hope. At times we felt like out hands were tied. . .it seemed like it was actually going nowhere."[13]

The Legal Angle

The initial refusal occurred in 1994. The second round of referrals were sent to Nelson and Anadale the following Fall. In the refusal letter from Jan Marx, a portion of the Illinois School Code, 105 ILCS 5/14-1.11a, is presented as evidence to support Nelson's decision to refuse a placement for Alex. (Appendix D) This section defines the eligibility criteria for services for "resident district; student". This statute reinforces the earlier argument of accepting out-of-district children under the protection of DCFS and denying out-of-district children with family involvement and living in out-of-home care.

Hilary Jamison, the QMRP overseeing Alex's case at this time, found another legal code from the State Board of Education subchapter F: Instruction for Specific Student Populations Part 226 Special Education effective August 10, 1992. In this code, the eligibility of children living in residential care facilities for special education services is described. Section 226.1155 states that "children resident in a residential care facility are entitled to all privileges and services provided by that district" (Appendix E) She presented this information to Robert Majors, Executive Director of SSCC, to use at an upcoming meeting concerning Alex's educational services.

The codes present contrasting interpretations of the eligibility for services for children with disabilities residing in out-of-home care. It remains unclear whether the

[13] Interview with author, October 24, 1996.

codes are describing the same or different criteria for residents of SSCC. They come from two different sources and thus present their definitions in dissimilar ways. One leans toward an in-district model thus supporting the viewpoint of SSCC personnel and the other bolsters the argument raised by the Nelson school district. The two codes never met, literally or figuratively and Alex was caught in the middle as he had been throughout this process for a less restrictive educational placement. Hope Duncan looked at it in this way,

> I don't care legally, what the law says, it is not an ethical or moral decision which I can live with and that's one of the reasons I kept pursuing it because I do not feel it is ethical for me as a person to be saying that this child doesn't deserve school. I really don't care what the law says. . .the child needed to be in school. It's unfair to him to be punished and that was the reason that I kept with it. People got real hung up on the law. I think people sometimes use the law in a way that it shouldn't be used. To me as an educator and a person you should look at this child and say this child has needs and how can we meet them not what can the law do to make it so I don't have to do that. [14]

Her comments articulate the need to go beyond what is written on paper and to look at the the individual case on its own merits. Decisions cannot always be made on the basis of what has come before. This circumstance also stresses the need for a more uniform review process when considering placement options. If the two parties had at least been "on the same page" maybe Alex would not have had to wait so long.

As Jan Max explained, administrators were hesitant to admit children with severe disabilities due to maintaining the natural proportion of these students in the community. Yet, in a community with a facility such as SSCC, what are natural proportions? Since its opening in 1975, SSCC has offered medical, rehabilitative, and educational services to its residents. Educational services are determined in this way,

> upon completion of the full case study [of the child by staff and rehabilitation specialists], an Individual Education Program (IEP) is developed for each child. This

[14] Interview with author, October 17, 1996.

codes are describing the same or different criteria for residents of SSCC. They come from two different sources and thus present their definitions in dissimilar ways. One leans toward an in-district model thus supporting the viewpoint of SSCC personnel and the other bolsters the argument raised by the Nelson school district. The two codes never met, literally or figuratively and Alex was caught in the middle as he had been throughout this process for a less restrictive educational placement. Hope Duncan looked at it in this way,

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> upon completion of the full case study [of the child by staff and rehabilitation specialists], an Individual Education Program (IEP) is developed for each child. This

[14] Interview with author, October 17, 1996.

program includes both short- and long-term goals, exercises, and learning activities which lead to the attainment of these goals. The IEP will also determine *where* (italics added) these goals will be met. Some of the children attend classes at a nearby public school, and [many]of them attend school at Sterling. (Appendix F)

Outside placement of SSCC residents is not a novel option. Precedent had been set with other children served in outside school programs that require special transportation and/or instructional services. The criteria for consideration is in health status. Alex was not considered for outside placement until his health had stabilized. Most preschool and school-aged residents around the clock nursing care thus curtailing any, and sometimes all, occasions for activities outside of the facility.

Enter the Advocate

A culmination of sorts occurred in September 1995 when Hilary Jamison sent Alex's parents information concerning advocacy organizations. She urged them to continue to push for admission into the public schools for their son. She provided the names of two advocacy organizations and adds "essentially, we have done what we can from here [at SSCC]. You, as Alexs' guardians, have the legal right to pursue the process" by contacting an advocate. The letter explains that "advocacy involves a person without direct contact with the situation who comes in and ensures that Alex receives services that he is entitled to."* It appears that the differences between Nelson and SSCC were not going to be resolved without additional intervention on Alex's behalf.

In February of 1996, a conference was scheduled to discuss the appropriateness of Alex's educational placement at SSCC. At that time, Alex's father reported that he had contacted Advocacy and Guardianship, an agency in Illinois that handles education

* Available from author.

related disputes, and signed a consent to release his son's records for their review. Another meeting was scheduled for April to update Alex's IEP goals and objectives. In the next two months, Advocacy and Guardianship agreed to accept the case and began proceedings to determine the most appropriate placement for Alex. In a letter dated May 21, 1996, Robert Majors notified personnel in Alex's home district that,

> Alex is still attending in-center school despite recommendations from the Speech pathologists, the psychologist, and Sterling staff that he be around peers [without disabilities]. Advocacy and Guardianship have forwarded information onto their lawyer, and alternative possibilities have been presented to the district [Nelson County] in order to meet the socialization goals written on the IEP. At present, as for the past four months, the IEP written on October 24, 1995 is out of compliance. (Appendix G).

An IEP is a legal document. Failure to meet any of its stipulations warrants action by legal or other means. Until this time, SSCC personnel had tried to negotiate with school administrators from the Nelson and Anadale public schools. Hope Duncan continued to provide assistance as well. It was not until intervention from the representative from Guardianship and Advocacy to influence and expedite the process.

Helen Morris sent an announcement for Alex's annual review on June 6, 1996. During this meeting, a recommendation was <u>again</u> made for public school placement. The representative from Lynchberg County reported that Alex's case was still in the hands of the advocate. A lawyer was also brought in by Guardianship and Advocacy assess whether or not Nelson Unit School District No.4 was responsible for serving Alex. Meanwhile, a space for Alex at Plains School in Anadale was close to becoming a reality. It appeared that the situation would be resolved in short order. What remained unclear was the final outcome. Would the case end when he began receiving educational services at Plains School or would it continue based on the lawyer's decision?

Resolution

In August, Hilary Jamison, now Resident Director at SSCC, received a letter from Hope Duncan announcing Alex's placement in the Anadale SPH program at Plains School. (Appendix H) He began attending on October 3, 1996. What could not be accomplished in approximately a year and a half was completed within six months with the involvement of the advocate. Nelson personnel did not participate in any type of correspondence with SSCC or attend Alex's annual review. It would seem that the administrators were waiting and hoping that the issue would go away. Hope Duncan, on the other hand, had remained on a twice monthly schedule with Dan Johnson.

Alex's new IEP, completed on October 21, 1996, states that in-center educational services were "too restrictive to meet [Alex's] language and social needs"* and he was now receiving educational services in an SPH classroom. The green light for Alex to attend Plains School was by no means the end of the story. As Dan Johnson explains,

> the advocate said "It's great that he's in Anadale but that has not stopped the legal process. Whether it be for Alex or somebody else similar" They [advocate and staff at Guardianship and Advocacy] didn't say he's in forget about it, I guess they felt they had done that much work they were going to follow it through. They're still trying. It might wind up that Nelson is responsible for him, could be next year that they make a decision or no, they are not. The advocate told him that their attorney interpreted it one way, Nelson's another way. Guess it depends what side you're on. You're looking for a loophole and that's what they're [Nelson] saying like oh no it says here and they use maybe one sentence out of a whole paragraph to justify. . .and that is when it turns into a legal issue and somebody has to decide. And I think that's where they [advocate and staff] are at right now.[15]

The Tireless Ally

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* Available from author.

[15] Interview with author, October 24, 1996.

In addition, without the continuing efforts of Hope Duncan, Alex might still be waiting for any type of outside placement. She persevered in the face of limited support from her superiors. She told me that she did not know Alex very well but continued to push out of a moral concern,

> All along Nelson says they have been advised by their attorney that they do not have an obligation to take a child who's legal residence is outside of this area. That is their *interpretation* [emphasis] of the law. That is all it is. Until an actual case, a law kind of a thing makes a precedent, it is not clear. The law is very gray on this. They use real broad range, they don't specify. . . I mean Alex had educational programming here [at SSCC] it wasn't like he didn't get anything, but it probably wasn't what should have been optimal and I guess my feeling on this is if parents get choices and they make a choice to serve their child here or in Anadale, if the parent makes that choice I feel very comfortable but when somebody tells me that there really is no choice for a child I get really angry. Because there should be a choice, that is what the whole thrust of inclusion is is opening choices. It is not supposed to narrow the span of choices. [16]

Dan Johnson and Helen Morris saw her involvement as more than an ethical imperative. Both reported Hope's involvement at SSCC on behalf of other outside school residents as well as frequent visits to the facility which often included observations of Alex. These observations increased at the time of the second refusal from Nelson. This coincided with the increasing possibility of Alex's placement in Anadale. In her position as social worker for the SPH program in Anadale, Hope was the primary liaison between the public school and the staff at SSCC. The extent of Hope Duncan's involvement probably lies somewhere in between. Regardless, without her persistence, the ending to this story might have turned out otherwise.

Alex at Plains

The staff at SSCC were overjoyed with the placement. The press of two years had finally paid off. Helen Morris, Dan Johnson, Hilary Jamison, and Hope Duncan proved

that they had the right idea in pushing for an outside placement for Alex. The space issue was resolved and the Anadale school district accepted this child with severe disabilities and complex medical needs. Alex was able to leave SSCC for several hours a day to receive educational programming in a less restrictive environment.

A Visit to Plains

I waited until Alex was sufficiently settled in to pay a visit to his new classroom. I accompanied Dan Johnson during his rounds to schools in the Nelson and Anadale area that provide educational services for residents of SSCC. Amid the hustle and bustle of teachers directing groups of children to the cafeteria, down the hall to the doors outside, and back from the bathrooms, there is Alex in his walker. He is smiling. Not just a hi, how are you kind of smile but one that beams. He directed these grins at children, approximately his own age, who were passing him on the left-hand side of the hallway. Alex received several smiles and waves in return for his efforts. He then continued down the hallway, deftly avoiding obstacles and grinning all the way.

Upon entering his classroom, the last one on the right at the end of a long hallway, I was immediately struck by the amount of space. It is a big room with ample space for wheelchairs and other adaptive equipment. A large mat dominates the center of the room. On one side of the mat is a moon shaped table with one student, a boy around eight or nine years of age, ambulatory, and non-verbal. An assistant was asking the student to make choices between pictures of everyday objects. Several times the student engaged in self-injurious behavior but was quickly redirected. These exchanges were supplied with an air of familiarity and a noticeable level of responsiveness to the student's distress.

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[16] Interview with author, October 17, 1996.

Voices were never raised. Encouragement and redirection toward more positive behavior were provided.

The room was well stocked with books, puzzles, and tapes that looked like they were used often and kept in good condition. Donna Addison, the teacher in Alex's room and a twenty year veteran in the field of special education for students with severe and profound disabilities, told me that many of the materials are also used by regular education students who come into her classroom to socialize with Alex and his classmates. I probed Donna about Alex's opportunities for socialization. She said that, at the present time, opportunities are limited to school assemblies and short periods of time during the day when other children come into the SPH classroom. The rationale used to push for a less restrictive placement for this child hinged upon the necessity of peers without disabilities for improvement in Alex's functioning in the social and communication areas. He was being exposed to peers but had limited interactions with them. Could placement in Nelson offer increased opportunities?

I did not see a posted schedule in the classroom but it appeared to be quiet time in the SPH classroom. One student was quietly sitting in his wheelchair on the far side of the big mat. He had a toy in his lap but was not engaged in any type of activity. The student from the table was now involved in free choice time, listening to a tape through headsets and the remaining student was finishing a gastrostomy feeding and was then placed on the large sized mat in a propped position. And Alex. . . he was still on the go! He was circling the room in his walker. He craftily avoided obstacles in his path. As Dan and I left we could hear Donna and one of her assistants calling after Alex to come back and get ready to leave to return to SSCC.

Instructional Objectives

Curriculum for students with severe disabilities often focuses on the context and mode of delivery than purely on the instructional objectives. The focus is on the "how" and the "where" of instruction instead of the "what". Looking at Alex's new IEP (October, 1996), I noticed objectives related to increasing Alex's toy play, signing repertoire, and greater independence in motor tasks. In addition, an abundance of language related objectives could be found. This is a result of the perseverance of the speech and language clinicians working with Alex. From the initial request to enroll in 1994, they had been advocating the need for his communication goals to be implemented in a more inclusive environment. These included following directions, responding to sounds, and recognition of words and signs. What was missing were specific strategies and procedures to ensure interaction with peers without disabilities in order for Alex to meet these objectives.

What struck me during my visit was how Alex initiated contact with adults, Donna, the assistants, Dan, and myself. He did not approach any of his classmates or acknowledge them in any way. Yet, he socialized a great deal in the hallway, IEP objective or no IEP objective. At SSCC, most occasions for interactions with peers without disabilities occurred with siblings during visits and/or with volunteers. Although Alex is receiving services in self-contained classroom assignment, some naturally occurring opportunities do exist for social interactions with peers without disabilities. Donna Addison spoke of increasing the amount of time same age peers spend in her classroom as well as the possibility for Alex to participate in school-wide activities in order to increase his opportunities for social interaction.

Looking Beyond Plains

Helen Morris suggests another solution to the need for more social opportunities for Alex.. In order for him to receive the most appropriate educational services, she advises that he needs to be placed in a more inclusive environment. Within the concept of LRE, there is a notion of a cascade of services which translates to a continuum of service delivery settings. A placement at a facility such as SSCC is labeled as the most restrictive. Each step along the cascade is a less restrictive option, culminating in placement in the child's neighborhood school in the classroom he would attend if he did not have disabilities.

There is a school located in the city of Nelson, five minutes from SSCC, that Helen Morris feels could accommodate Alex's needs in an inclusive kindergarten setting. With the support of an aide, whether from SSCC or through the Nelson school district, Alex could participate in such a setting. Alex's current placement in a self-contained classroom in an Anadale elementary school, while offering some opportunities for interactions with peers, does not realize the intent of the rationale for seeking a placement outside of SSCC. The Nelson classroom could greatly increase the likelihood of social skills acquisition as well as learning from peer models that are not readily available at either SSCC or Plains School.

Conclusions

Alex continues to receive educational services in a self-contained classroom within a community elementary school. His parents are satisfied with the placement at Plains School. Yet, the words of Helen Morris resonate, why can't Alex receive services in a more inclusive environment? Initially, staff at Plains and SSCC were unsure of how

Alex would adjust to his placement. To date, he has not manifested any medical or behavioral problems. All reports from Donna Addison and Hope Duncan are positive. Every morning Alex wheels himself to SSCC's front door to wait for the school bus.

What Have We Learned Or Has Anything Changed?

Alex continues to outlive his life expectancy. Individuals with Marshall-Smith Syndrome typically do not survive past infancy. At the age of five, his health is stable. Dan Johnson raised the point that the "reality of situation with Alex's diagnosis you don't know how long he's going to live and that was always a fear of mine that maybe he wouldn't make it because of the time it took to get into public school. . .too bad couldn't get him there two years ago."[17] In addition, the comments of Helen Morris concerning Nelson's initial refusal provide some guidance for Alex and others like him,

> Nelson does not really want to take Sterling kids. I mean I'm not sure why. They've had them in the past. Particularly in the early childhood program. It was the preschool physically, health impaired class that those kids came into and I'm not sure if because of inclusion they don't want to take up the space, most of the kids would be more involved, they'd be afraid that they would have a sudden influx of Sterling Special Care kids coming over to Nelson.[18]

For all the support and enthusiasm for the theory of inclusion, practice is not as straightforward. Accepting children with more severe disabilities and complex health needs is viewed as a strain on district resources and upsetting natural proportions. Yet, Anadale's answer is housing all of SSCC residents in self-contained classrooms. What is the most effective way to deal with these conflicting views? An answer is not clear-cut at this time. There is no written or agreed upon policy for accepting children like Alex that reside at SSCC.

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[17] Interview with author October 24, 1996.

The presence of a residential facility for children with severe disabilities and complex health needs in a community embracing inclusion presents several unsettling questions. An apparent contradiction exists between being an adherent to the theory of inclusion and carrying it out in practical terms. Many recommended practices in the field of early childhood special education face similar difficulties. Time is necessary for a theory to catch on and be implemented by practitioners in the recommended manner. Inclusion advocates posit the need for all children with disabilities to attend their neighborhood schools in classrooms with same age peers. A child such as Alex could be viewed as requiring a large amount of district resources due to his complex needs.

The administrators from Nelson and Anadale, Jan Marx and Barbara Caldwell respectively, offer a glimpse into the gray area at the heart of this case and the difficulty inherent in translating theory into practice. The use of legal codes, the lack of space in both districts, the functioning level question, all illustrate the reality of moving toward inclusive placements. A policy needs to be place for the process to be fluid for all SSCC residents referred to outside public school. Hope Duncan captures the intricacy of Alex's circumstances and the lack of policy to guide future situations,

> I would hope that two special education directors are going to be able to come to some reasonable negotiation on how children in the future are going to be handled because they [the children at SSCC] are going to be the losers. I mean Alex should have had, he had educational programming here it wasn't like he didn't get anything, but it probably wasn't what should have been optimal and I guess my feeling on this is if parents get choices and they make a choice to serve their child here or in Anadale, if the parent makes that choice I feel very comfortable but when somebody tells me that there really is no choice for a child I get really angry. Because there should be a choice, that is what the whole thrust of inclusion is is opening choices. It is not supposed to narrow the span of choices. . . I think it was a one person situation. . . that's why this is not a resolved issue, in reality although I helped Alex it didn't change anything for anybody

[18] Interview with author, October 16, 1996.

else. But I said look we've only solved one problem here for one student, this issue keeps happening. That's why there needs to be some plan and that's why I got stuck in the middle, Jack, myself, and the people here.[19]

There is talk of pursuing Alex's case through legal avenues as well as Helen Morris' idea of requesting a more inclusive classroom at either Plains School or in a Nelson elementary school. When I mentioned this to Dan Johnson, he reacted with surprise. It appeared that he had little knowledge of the site in Nelson and was considering advocating for Alex's placement in the kindergarten at Plains School. He summed it up by saying that if Alex is able to Plains School, in general, and Donna Addison's class, in particular, there is no reason to keep him out of a regular education classroom. Regardless, if Alex's case goes to the courts, it could take several years to gain a more inclusive placement. It could be settled too late to have an impact on Alex due to his medical conditions and limited life expectancy.

It must be pointed out that money was never an obstacle to Alex's placement. His home county agreed to provide the necessary funding and supports from the initial request to enroll in 1994. Yet, one of Nelson's main arguments was based on monetary grounds in terms of the use of scarce resources to meet Alex's needs. The problem was one of space. Space was available for Nelson and Anadale's own youngsters, not for out-of-district children. Space was available for children with less severe disabilities, not for one with multiple complex needs. The lack of space in Anadale's early childhood program coupled with the need for a waiver for Alex to be placed in Donna Addison's classroom were the primary reasons that the process took two years to come to fruition. To reiterate, the existence of a facility like SSCC in any community necessitates that

[19] Interview with author, October 17, 1996.

these questions be dealt with in a more systematic manner so that the children are not penalized for indecision on the part of the adults in responsible for facilitating the process. Even though these children are unable to live at home with their families, plans should be in place for their inclusion into neighborhood schools. Whether the district within which the facility is located chooses to follow previously established guidelines or create new ones specifically for SSCC residents, particularly for those of preschool age, this issue must be settled.

What remains to be seen is what will happen to the next Alex. Will the process take two years? Will Nelson be more willing to accept this child? Will Anadale have more slots available? Will they continue to be served in self-contained classrooms or in more inclusive regular education settings? These questions must be answered in a decisive fashion in order to avoid situations like Alex's. SSCC is not going to go away. Children like Alex will continue to be admitted and referred to public school. The theory of inclusion and the practice of placement in the least restrictive environment will continue, as is being done around the country. It is a movement with many proponents, many prominent in the Nelson-Anadale community. What is needed is for its implementation to catch up with its ideology.

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APPENDIX A

September 20, 1994

Mr.

Dear Mr.

This letter is to clarify School District's decision regarding your request to enroll a resident of your facility whose parents reside in , Illinois into our district's early childhood program. As you know we are mandated to serve only those students who are wards of DCFS or students who have parent/guardians that reside in our district. At this time we are not mandated to serve students whose parents do not reside in our service area, therefore we have made the decision not to accept as a student in our early childhood program.

After much deliberation we feel that there were two main reasons for this decision. The first is that the additional supports and aides required to serve this student is beyond our current resources as we are at capacity serving our own students. The second reason is that we are very committed to serving students in their home schools and accepting tuition students creates an unequal proportion of students with severe disabilities in these schools.

We appreciate the cooperative relationship that we have had with you in the past and will work to maintain this relationship. Also, I will be glad to discuss this decision with you if you feel that it is necessary.

Sincerely,

E

Director, Special Education

cc: , Assistant Director, Special Education

BEST COPY AVAILABLE

Board of Education
Administrative Offices

APPENDIX B

February 8, 1995

Dear

Our social worker, , has told me that a representative from 's SPH program will be invited to a staffing for . She indicated that it is possible that a recommendation will be made for public school placement in our SPH program.

After having looked at the psychological report, it appears that would be eligible for services in the SPH program. However, at the present time, we have no slots available for out of district students in our preschool SPH program at School. We may have a slot for in the 95-96 school year, so feel free to contact us next fall to inquire about this possibility.

If you have further questions, please feel free to contact me.

Sincerely,

cc:

APPENDIX C

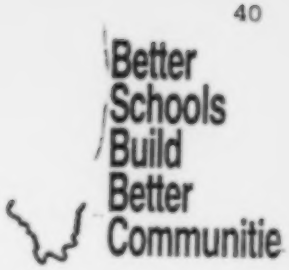
Clinical Impressions and Prognosis:

Based on progress to date, _'would appear to be cognitively functioning at a higher level than previously indicated by the Uzgiris-Hunt Scales of Infant Psychological Development (1971). His hearing loss and physical disabilities limit his ability to functionally communicate by conventional means. ____'auditory and physical disabilities limit his ability to perform on standardized tests. Prognosis for increasing functional communication skills appears to be fair to good if (receives the services outlined below. Without the appropriate services prognosis is significantly poorer.

Recommendations:

1. Educational placement in the least restrictive environment with age appropriate normal peers.
2. Increase the use of the hearing aid across the day.
3. Increase the use of the Passy-Muir device across the day.
4. Increase the use of picture communication across the day.
5. Speech and language reevaluation using the nonstandardized communicative development scales as presented in **Assessing Communication, Cognition, and Vocalization in the Prelinguistic Period.** Infant and Young Children, 7, (1995).
6. Implement pre-feeding therapy program.

Graduate Clinician Supervising Speech-Language Pathologist



APPENDIX D

September 15, 1995

Mr.
Executive Director

Dear Mr.

This letter is a response to your request to refer to our special education, early childhood program. At this time we are not accepting students whose parents do not reside in our district. This decision is based on the Illinois School Code, 105 ILCS 5/14-1.11a. Resident district; student.

If you have not done so, I suggest you contact School District which has a tuition program for out-of-district students who reside at the Special Care Center.

Sincerely,

Director, Special Education

requirements of this Article, who has the required special training in the understandings, techniques, and special methods of instruction for children who because of their handicapping conditions are placed in any program provided for in this Article and who works in such program.

Laws 1961, p. 31, § 14-1.10, added by Laws 1965, p. 1948, § 1, eff. July 25, 1965; P.A. 81-343, § 1, eff. Jan. 1, 1980. Amended by P.A. 82-454, § 1, eff. Sept. 15, 1981.

Formerly Ill.Rev.Stat.1991, ch. 122, ¶ 14-1.10.

5/14-1.11. Resident district; parent; legal guardian

§ 14-1.11. Resident district; parent; legal guardian. The resident district is the school district in which the parent or guardian, or both parent and guardian, of the student reside when:

(1) the parent has legal guardianship of the student and resides within Illinois; or

(2) an individual guardian has been appointed by the courts and resides within Illinois; or

(3) an Illinois public agency has legal guardianship and the student resides either in the home of the parent or within the same district as the parent; or

(4) an Illinois court orders a residential placement but the parents retain legal guardianship.

In cases of divorced or separated parents, when only one parent has legal guardianship or custody, the district in which the parent having legal guardianship or custody resides is the resident district. When both parents retain legal guardianship or custody, the resident district is the district of the parent who claims the child as a dependent on his or her federal income tax return.

When the parent has legal guardianship and lives outside of the State of Illinois, or when the individual legal guardian other than the natural parent lives outside the State of Illinois, the parent, legal guardian, or other placing agent is responsible for making arrangements to pay the Illinois school district serving the child for the educational services provided. Those service costs shall be determined in accordance with Section 14-7.01.

Laws 1961, p. 31, § 14-1.11, added by P.A. 87-1117, § 1, eff. Jan. 1, 1993.

Formerly Ill.Rev.Stat., ch. 122, ¶ 14-1.11.

5/14-1.11a. Resident district; student

§ 14-1.11a. Resident district; student. The resident district is the school district in which the student resides when:

(1) the parent has legal guardianship but the location of the parent is unknown; or

(2) an individual guardian has been appointed but the location of the guardian is unknown; or

(3) the student is 18 years of age or older and no legal guardian has been appointed; or

(4) the student is legally an emancipated minor; or

(5) an Illinois public agency has legal guardianship and has placed the student residentially outside of the school district in which the parent lives.

In cases where an Illinois public agency has legal guardianship and has placed the student residentially outside of Illinois, the last school district that provided at least 45 days of educational service to the student shall continue to be the district of residence until the student is no longer under guardianship of an Illinois public agency or until the student is returned to Illinois.

The resident district of a homeless student is the Illinois district in which the student enrolls for educational services. Homeless students include individuals as defined in the Stewart B. McKinney Homeless Assistance Act.[1]

Laws 1961, p. 31, § 14-1.11a, added by P.A. 87-1117, § 1, eff. Jan. 1, 1993. Amended by P.A. 88-134, § 5, eff. July 27, 1993.

Formerly Ill.Rev.Stat., ch. 122, ¶ 14-1.11a.

[1] See, generally, 42 U.S.C.A. § 11301 et seq.

5/14-1.11b. Resident district; applicability

§ 14-1.11b. Resident district; applicability. The provisions of Sections 14-1.11 and 14-1.11a shall be used to determine the resident district in all cases where special education services and facilities are provided pursuant to Article 14.

Laws 1961, p. 31, § 14-1.11b, added by P.A. 87-1117, § 1, eff. Jan. 1, 1993.

Formerly Ill.Rev.Stat., ch. 122, ¶ 14-1.11b.

5/14-2. § 14-2. Repealed by Laws 1965, p. 1948, § 2, eff. July 21, 1965

5/14-2.01. § 14-2.01. Repealed by P.A. 82-362, § 2, eff. Sept. 2, 1981

5/14-3. § 14-3. Repealed by Laws 1965, p. 1948, § 2, eff. July 21, 1965

5/14-3.01. Advisory Council

§ 14-3.01. Advisory Council. There is hereby created a special education Advisory Council on Education of Handicapped Children to consist of 15 members appointed by the Governor, who shall hold office for 4 years. No person shall be appointed to serve more than 2 consecutive terms on the Advisory Council. The terms of members serving at the time of this amendatory Act of 1978 are not affected by this amendatory Act. The membership shall include a handicapped adult, 2 parents of handicapped children, a consumer representative, a representative of a private provider, a teacher of the handicapped, a regional superintendent of an educational service region, a superintendent of a school district, a director of special education from a district of less than 500,000 population, a professional affiliated with an institution of higher education, and a member of the general public and the Director of Special Education for the Chicago Board of Education, as an ex-officio voting member. Of the members appointed after the effective date of this amendatory Act of 1978, the Governor shall appoint one member to an initial term of 2 years, one member to an initial term of 3 years and one member to an initial term of 4 years. Vacancies shall be filled in like manner for the unexpired balance of the term.

Because of the responsibility of the Department of Children and Family Services, the Department of Mental Health and Developmental Disabilities and the Department of Rehabilitation Services for special education programs, the Director of the Department of Children and Family Services and the Director of the Department of Mental Health and Developmental Disabilities and the Director of the Department of Rehabilitation Services or their designees shall be ex-officio voting members of the Council. In addition, the

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567, § 1, eff.
1992.

Formerly Ill.

[1] 20 U.S.C.A.
[2] 29 U.S.C.A.
[3] 775 ILCS 5

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APPENDIX E

Mr. _____

ENCLOSED IS INFORMATION FOR YOUR MEETING ABOUT _____. THE TOP PAGE IS THE CODE THAT I CITED, REGARDING RESIDENT DISTRICT. THE PART LABELED SPECIAL EDUCATION I FOUND IF IT SEEMS TO RELATE.

IT APPEARS THAT _____ IS ARGUING THAT THEY ARE NOT THE RESIDENT DISTRICT. WE AGREE - THEY AREN'T LEGALLY THE RESIDENT DISTRICT. _____, IL IS & ARE WILLING TO PAY FOR SCHOOL SERVICES.

THE CODES THAT I COPIED SEEM TO IMPLY THAT CHILDREN IN A RESIDENTIAL FACILITY ARE ENTITLED TO ALL SERVICES IN THAT DISTRICT. IT APPEARS TO STILL BE UP FOR INTERPRETATION DIFFERENCES, BUT IT WOULD PROVIDE A POINT TO ARGUE.

THANKS

I

I SENT THIS INFORMATION TO _____.

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Title 23: Education and Cultural Resources

Subtitle A: Education

Chapter 1: State Board of Education

Subchapter F: Instruction for Specific Student Populations

Part 226
Special Education

Effective Date; August 10, 1992

Section 226.1150 Criteria for Eligibility of Children

An individual child shall be eligible for special education services under Section 14-7.03 if he or she meets all of the following criteria:

a) He/she is a resident of one of the residential care facilities described in Section 226.1112.

b) He/she would not be a resident of that school district except by virtue of his or her placement in one of the residential care facilities described in Section 226.1112.

c) He/she has been declared eligible according to this Part.

Section 226.1155 Resident Children Eligible for All Privileges

Children resident in a residential care facility are entitled to all privileges and services provided by that district.

hild's IEP through one-on-one training, small group nteraction, and daily group activities.

Our nursing staff directs the medical care of each hild twenty-four hours a day. Our physicians make cheduled visits to the center and are on emergency call. ach nursing assistant is responsible for the daily hysical care (bathing, feeding, and dressing) of his/her hildren, and for providing the children with a living rea that is warm and personal. The education goals set or our children are reinforced by the nursing staff, and ur education staff is involved in the daily nursing care f our children.

Mealtimes are very important to the children's total rogram. Our food service staff takes care to provide not nly nutritionally balanced meals, but also attractive and aried menus. The individual menus based on personal ietary needs are planned by our registered dietitian. he handling, positioning, and care each child receives uring feeding help to assure not only adequate food ntake, but also improved eating skills and a time of ocial growth.

In addition to these daily activities, our children njoy periodic outings. These outings include visits to arks and playgrounds, shopping trips, and field trips to ommunity facilities and attractions. These experiences elp to broaden the children's awareness of, and interest n, the community environment.

Admission Policies

Admission to Special Care Center is open to all children from birth. Residents may remain in the center upon a physician's recommendation as long as the placement remains appropriate. Race, creed, sex, or national origin have no bearing on acceptance, which is based on the individual needs of the child and the home's capability to meet these needs. When an application or referral for admission is reviewed, a medical and social history, an immunization record, a determination of legal and financial responsibility, and contact with the resident school district, are required. Various state agencies and federal programs are available to help defray the cost of care during residency at the center.

Evaluation and programming are begun immediately upon admission to the center, and the progress of these programs is monitored throughout the child's stay. Re-evaluations are made routinely to assure the appropriateness and effectiveness of the programming. Parents are welcome to visit at any time. No appointment is necessary for any visits within the center.

Special Care Center is licensed by the State of Illinois Department of Public Health as a special purpose facility for the care of developmentally disabled children in need of skilled nursing care. It meets all regulations and standards for services, equipment, and physical plan; and it is approved to participate in Title XIX, Medicaid.

For further information concerning admission, fees, and services, contact:

Executive Director

Special Care Center

Appendix F

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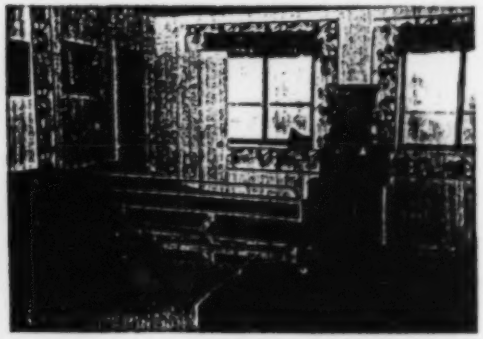
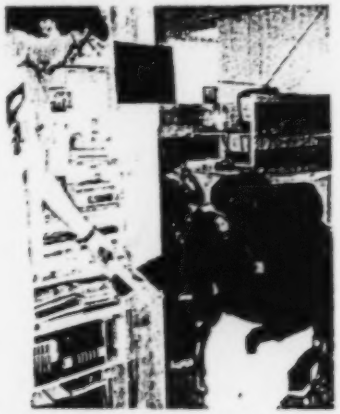
Special Care Center is a home for children who are severely and profoundly multiply handicapped. The staff consists of skilled professionals, paraprofessionals, and trained nursing assistants who, with other support staff, provide a caring atmosphere in which the children's physical, medical, nutritional, mental, emotional, and social needs are met.



The entire staff works toward creating a friendly and stimulating homelike environment. The facility is bright, attractive, colorful, and well-kept. The daily care the children receive emphasizes the staff's belief in each child's rights to develop to his/her full potential. We believe that every child should have the encouragement and support necessary in order to establish warm personal relationships, to enjoy living activities, and to gain a positive self-image.

Education and Nursing

To assure that each child's special needs are served, individual programs are developed. The educational and nursing programs work together, and are designed to create an atmosphere in which maximal growth is attained in all areas of development.



Our special education programs result from a full case study conducted by the local school district where the parents reside. This full case study analyses the child's capabilities in motor development, self-help, socialization, communication, and cognition. Evaluations may also be completed by our licensed physical, occupational, or speech therapists, or by our psychologist. Upon completion of the full case study, an Individual Education Program (IEP) is developed for each child. This program includes both short-and long-term goals, exercises, and learning activities which will lead to the attainment of these goals. The IEP will also determine where these goals will be met. Some of the children attend classes at a nearby public school, and some of them attend school at .

When a child turns eighteen, he/she is eligible to participate in a special day training program. The work study portion includes experience in the laundry, office, book store, and restaurant. Other daily programs include communications, recreation leisure, physical therapy, and a video center.

The daily educational and training programs emphasize activities in the areas of sensory motor integration, self-help, language and communication, and motor development and positioning. Because self-awareness and environmental awareness are necessary for a child to make gains in any development area, we concentrate on stimulation of the senses of taste, touch, smell, hearing, and sight. We encourage the children to participate, as far as their capabilities will allow, in feeding, dressing, and bathing themselves. Improvement in these skills maximizes independence and self-care. We work to develop a useful communication system for each individual child. This may include signing, natural gestures and verbalizations, communication boards and books, and/or spoken words.

Motor development programs are provided, particularly range of motion, in order to maintain and improve motor skills. We work toward proper body alignment for every child, because correct body alignment is vital to physical development and functioning. We also involve our children in creative play with toys appropriate for motor skill development.

Our education staff members work to fulfill each

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Special Care Center

APPENDIX G

May 21, 1996

re:

Dear

On October 24.1995 the annual IEP and interim IEP for were held at Swann Special Care Center. Present were , Ed. Services D Director of representative. University of Illinois, Director and and teachers. The IEP was listed as an interim beginning 11/03/95, contingent upon entering into public school, no later than January, 1996.
As of this date is still attending Incenter school. despite recommendations from the Speech pathologists, the psychologist, and staff that he be around peers. Advocacy and Guardianship have forwarded information onto their lawyer, and alternative possibilities have been presented to the district in order to meet the socialization goals written on the IEP. At present, as for the past four months, the IEP written on October 24,1995 is out of compliance.

Sincerely,

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APPENDIX H

August 15, 1996

Ms. QMRP

re:
BD:

Dear

It has taken a long time for me to be able to write this letter to you, but it is one I write with a great sense of satisfaction. Our Special Education Director, has received a waiver from ISBE for which will allow placement in classroom at this school year. presently has five students ages 7 to 10 who would be in closest proximity to age. taught the younger students in our program since it began in 1978.

In order to proceed your assistance is requested to contact parents to determine if they are still interested in his attending public school. I would be happy to arrange a visit to the classroom after school begins for students on Thursday, August 29. If the family wishes to proceed with public school placement, contact will need to be made with the home school district to assure they will fund educational and transportation costs. The home school district should contact our Program Director/Assistant Director of Special Education to discuss financial information and transportation arrangements which they will need to make for . I spoke with today on the phone when I was attempting to reach you, and asked her about the length of school day she felt would be best for , full or half day. It was her feeling it would be best to start on a half day schedule and see how he did. This option is available as far as our school program, but would need to be discussed with transportation to assure they could accomodate it, and if morning or afternoon attendance were both possible. The school day at is 8:15am to 3pm. Since is an out-of-district student, if the parents or school district decide to postpone his starting school, he could be accepted on a space available basis in the future.

In addition to the above, the following records for will be needed as soon as possible:

Psychological Evaluation(s)
Social Developmental Study/Social History
MDC Report
Current IEP and progress reports
Vision Reports

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Hearing Information/Reports
Current Medication orders from SSCC
Needed prior to school entry - school physical, including immunizations and a copy of ___ birth certificate issued by the county courthouse where ___ was born (parents will need to get this if they do not already have one)

Following your contacts with ___ parents and home school district to determine interest in public school attendance, and our staff's review of his educational information, I will be in contact with you to discuss necessary procedures leading to school placement. If you have questions, please feel free to contact me or ___. Thank you for your assistance with this referrral, and I look forward to hearing from you.

Sincerely,

School Social Worker, SPH Program

cc:
QMRP

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